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ABSTRACT

Intended for parents of developmentally disabled children, the handbook provides information on speaking to community groups. The parent speaker program is designed to correct public misconceptions about disabilities, help people learn more about disabilities, and share practical information. The first section of the handbook provides basic information on mental retardation, epilepsy, autism, and cerebral palsy; reviews myths and stereotypes; and highlights aspects of federal laws and financial assistance. Suggestions for delivering the basic talk are offered. The second section includes fact sheets on mental retardation, cerebral palsy, autism, epilepsy, blindness, and deafness. Each fact sheet considers incidence, etiology, characteristics, management and resources. The third section lists resources for specific disabilities. Suggestions for getting started as a parent speaker touch upon making contact with the community and reaching out to other parents. Appended is a guide designed to help establish parent speaker programs. (CL)

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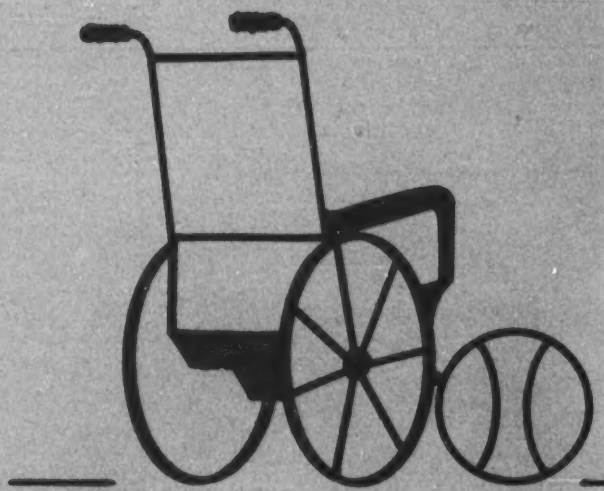
REACHING OUT

M. Kay Blackard and Elizabeth T. Barsh

ACHIEVING COMMUNITY INVOLVEMENT with DEVELOPMENTALLY DISABLED CHILDREN:

A STEP-by-STEP APPROACH



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REACHING OUT

M. Kay Blackard & Elizabeth T. Barsh

WILLOUGHBY WESSINGTON
- 1982 -

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Mercer Island, WA 98040

M. Kay Blackard and Elizabeth T. Barsh are well known for the development of innovative services for developmentally disabled children and their families. They have conducted regional workshops and seminars on family service programs, directed research projects related to handicapped children, instructed and supervised university students, and have published in professional journals, magazines and books. This book expresses their belief in the rights of developmentally disabled children and offers the reader a practical approach to improving community attitudes.

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A Note to Parents

Before you read this handbook, we thought you should know how it came about. For a number of years, we have worked closely with parents of developmentally disabled children. We have seen the problems families face due to negative community attitudes toward disabilities. We have shared the hurt and dismay that accompanies rejection and insensitivity, and we know the difference that community acceptance and support can make.

We've also seen how effective parents can be as advocates for their children. Their efforts have resulted in many needed and significant changes. It seemed to us that parents were uniquely qualified to promote more positive community attitudes, and that they should have more representation in community education efforts. We felt that a direct person to person approach would be an effective way for parents to reach out to community groups.

This conviction led us to the development of a Parent Speakers Program. With the help of an interested group of parents, we began putting together training materials, training parent speakers, and giving talks to community groups.

This handbook grew out of these efforts. It has been successfully used by many parent speakers. It is a basic information source for all parent speakers. It will alert you to the types of community services available, and provide you with information about developmental disabilities. It will help you learn to speak effectively to community groups. And it will show you how you can begin to impact your community.

We hope you, too, will find this handbook useful, and we welcome your participation as a parent speaker.

M. Kay Blackard

M. Kay Blackard, RN, MSW

Elizabeth T. Barsh

Elizabeth T. Barsh, MSW

Becoming a Parent Speaker

what's it all about?

It's about you and the impact you can make on your community.

It's about helping people understand the needs and rights of disabled persons.

It's about improving public attitudes.

It's about helping parents take positive steps to help their children.

why you?

Why are you the ideal person to do this?

Because you are the parent of a disabled child.

Because you have first hand knowledge and experience.

Because you know what you're talking about.

Because people will listen to what you have to say.

what you do

You give talks to community groups.

You help people learn more about disabilities.

You correct myths and misconceptions.

You get people in touch with resources they need.

You share some of your own experiences.

So you're probably not a professional public speaker.

You don't need to be.

All that's needed is a willingness to share.

PARENT COMMENTS

I'd never done anything like this before.

The group was really with me.

It was fun.

I can't believe it's really me giving these talks.

What a friendly audience.

It was a neat experience.

Once I got started, I hated to stop.

Getting Started

This handbook was put together with the help of other parent speakers. It contains all the information you'll need. We hope you will take the time to look it over thoroughly. You'll be using this handbook not only when you get started in the program, but also each time you give a talk. So it's very important not to skip around. Just follow the handbook page by page.

The handbook has three main parts: the Talk, Fact Sheets, and Resource Sheets.

- The Talk provides information on all developmental disabilities. It includes: definitions of each disability; myths, misconceptions and stereotypes about disabilities; laws and resources available to help disabled persons and their families.

- The Fact Sheets briefly describe six developmental disabilities: Mental Retardation, Cerebral Palsy, Autism, Epilepsy, Blindness, Deafness. Each Fact Sheet covers facts, figures, characteristics, causes, management, and resources.

- The Resource Sheets list key contacts for additional information and/or help.

We've also included practice exercises to help you learn how to give the talk, utilize the Fact Sheets, provide resource information, and handle questions and answers.

Please be sure to do the practice exercises, not just read them. You can try them out on your own, or with the help of another parent speaker.

Sound like a lot of work? It really isn't. You'll be surprised how quickly it all falls in place.

Your decision to become a parent speaker is a beginning to an exciting new adventure. We hope this handbook helps you along the way. We look forward to your joining those other parent speakers who have reached out to their community.

The Talk

The prepared talk that you'll find beginning on the next page was developed with the help of parent speakers.

It's important that you give this talk as written. Other parent speakers have found that using this prepared talk is the easiest and most effective way of getting information across. And they felt that the information it contained was interesting and important for audiences to hear.

If there is a word here and there that doesn't seem natural to you, by all means use your own wording. There'll be an opportunity for you to expand on other points or bring up your own thoughts and experiences during the question and answer time.

Well, enough talk about the talk. You'll have a better idea of what it's all about after you've read through it.

The Parent Speaker Talk

MY CHILD'S NAME IS _____. HE IS _____ YEARS OLD.

HE IS ONE OF MORE THAN 35 MILLION HANDICAPPED PERSONS IN THIS COUNTRY.

HE HAS (briefly describe) _____.

AT ONE POINT IN MY LIFE I KNEW VERY LITTLE ABOUT DISABILITIES.

NOW, AS A PARENT OF A DEVELOPMENTALLY DISABLED CHILD, I WANT TO SHARE WITH YOU. I WANT TO TELL YOU ABOUT WHAT PARENTS HAVE LEARNED AND EXPERIENCED.

Definitions

LET'S FIRST TALK ABOUT DEFINITIONS. BY DEFINITION, DEVELOPMENTAL DISABILITIES ARE THOSE HANDICAPPING CONDITIONS WHICH START BEFORE THE AGE OF 22. THEY MAY BE MENTAL OR PHYSICAL HANDICAPS.

THEY ARE LIKELY TO CONTINUE INDEFINITELY.

THEY MAKE UP A SUBSTANTIAL HANDICAP FOR THE INDIVIDUAL INVOLVED.

MENTAL RETARDATION, CEREBRAL PALSY, AUTISM, EPILEPSY & SIMILAR HANDICAPS CAN ALL BE DEVELOPMENTAL DISABILITIES.

Numbers

NUMBERS SOMETIMES GIVE US A BETTER HANDLE ON WHAT WE'RE DEALING WITH.

1 IN EVERY 10 AMERICANS HAS A MENTALLY RETARDED PERSON IN HIS FAMILY.

ABOUT 1 IN EVERY 100 PERSONS IN THIS COUNTRY HAS EPILEPSY.

ABOUT 4 OUT OF EVERY 10,000 CHILDREN HAVE AUTISM.

ABOUT 6 OUT OF EVERY 1,000 BABIES BORN HAVE CEREBRAL PALSY.

NUMBERS DON'T TELL US EVERYTHING. EACH OF THESE DISABILITIES AFFECTS PEOPLE DIFFERENTLY.

Mental Retardation

MENTALLY RETARDED PERSONS MATURE MORE SLOWLY THAN MOST PEOPLE.

BUT THEY CAN AND DO LEARN.

MENTAL RETARDATION DOESN'T MEAN JUST A LOW I.Q.

IT ALSO MEANS THE PERSON DOESN'T BEHAVE IN A WAY THAT WOULD NORMALLY BE EXPECTED FOR HIS AGE.

THERE ARE SEVERAL DEGREES OF RETARDATION.

WE HAVE FOUND THAT ALL MENTALLY RETARDED PERSONS BENEFIT FROM EDUCATION AND TRAINING.

Epilepsy

THE WORD EPILEPSY IS USED FOR NERVOUS SYSTEM DISORDERS THAT RESULT IN SEIZURES.

WHEN A PERSON WITH EPILEPSY HAS A SEIZURE THERE MAY BE MUSCLE CONVULSIONS.

THERE MAY BE PARTIAL OR TOTAL LOSS OF CONSCIOUSNESS.

THIS MAY LAST FROM SEVERAL SECONDS TO SEVERAL HOURS.

IT ALL DEPENDS ON THE TYPE OF SEIZURE.

80% OF PEOPLE WITH EPILEPSY CAN BE TOTALLY OR ALMOST TOTALLY FREED FROM SYMPTOMS THROUGH CONTINUING TREATMENT.

Autism

PERSONS WITH AUTISM HAVE SEVERE COMMUNICATION AND BEHAVIOR PROBLEMS.

THEY ARE UNABLE TO RELATE TO OTHER PEOPLE IN A NORMAL WAY.

THEY MAY BE MORE INTERESTED IN OBJECTS THAN IN PEOPLE.

AUTISM IS 4 TIMES MORE LIKELY TO OCCUR IN BOYS. IT SEEMS TO BE DUE TO A PROBLEM IN THE CENTRAL NERVOUS SYSTEM. THE EXACT TYPE IS NOT KNOWN.

AUTISM USUALLY APPEARS DURING THE FIRST 3 YEARS OF LIFE. IT IS SOMETIMES SUSPECTED AS EARLY AS A FEW WEEKS OR MONTHS AFTER BIRTH.

PEOPLE WITH AUTISM CAN BENEFIT FROM SPECIAL EDUCATION.

Cerebral Palsy

THE WORD CEREBRAL PALSY IS USED FOR A GROUP OF NERVOUS SYSTEM DISORDERS THAT AFFECT THE WAY MUSCLES WORK.

PEOPLE WITH CEREBRAL PALSY ARE NOT ABLE TO CONTROL MUSCLE MOVEMENTS.

SOMETIMES THEY HAVE HEARING AND VISION PROBLEMS AS WELL.

BECAUSE OF THE MOTOR PROBLEMS, SPEECH MAY BE DIFFICULT.

THERE ARE SEVERAL TYPES OF CEREBRAL PALSY AND PEOPLE MAY BE AFFECTED IN DIFFERENT WAYS.

PHYSICAL THERAPY, SPEECH THERAPY, AND OCCUPATIONAL THERAPY CAN BE PARTICULARLY HELPFUL.

Problems

DEVELOPMENTALLY DISABLED PEOPLE ARE FOUND IN ALL TYPES OF FAMILIES.

IT CAN LITERALLY HAPPEN TO ANY OF US.

AS A PARENT, I CAN TELL YOU THAT THESE DISABILITIES CAN CAUSE SOME REAL PROBLEMS FOR FAMILIES.

JUST TO MENTION A FEW PROBLEMS:

GETTING ACCURATE INFORMATION

GETTING APPROPRIATE SERVICES

DEALING WITH MYTHS, MISCONCEPTIONS, & STEREOTYPES ABOUT HANDICAPS.

Myths - Misconceptions - Stereotypes

ONE OF THE REASONS THAT WE SHOULD BE CONCERNED ABOUT MYTHS AND MISCONCEPTIONS IS THIS:

WHAT WE BELIEVE IS TRUE ABOUT DISABILITIES, CHANGES HOW WE ACT TOWARD DISABLED PERSONS.

HERE ARE SOME EXAMPLES:

NOT TOO LONG AGO, IN MANY STATES, PERSONS WITH EPILEPSY WERE NOT ALLOWED TO GET MARRIED.

A FEW YEARS AGO, ONE STATE IN THIS COUNTRY INTRODUCED A BILL CALLING FOR THE MERCY KILLING OF ANYONE WITH AN I.Q. BELOW 50.

FOR MANY YEARS, DISABLED PEOPLE HAVE BEEN DISCRIMINATED AGAINST AND DENIED JOBS THEY WERE CAPABLE OF DOING.

BEFORE 1975, ONE MILLION HANDICAPPED CHILDREN IN THIS COUNTRY HAD NEVER SET FOOT IN A PUBLIC SCHOOL.

WE MUST RE-THINK OUR BELIEFS AND VALUES ABOUT DISABILITIES.

PUBLIC ATTITUDES SOMETIMES LIMIT DISABLED PERSONS' ABILITY TO BE INDEPENDENT..... MORE SO THAN ANY DISABILITY COULD!

HERE ARE SOME EXAMPLES OF MYTHS:

THAT ALL MENTALLY RETARDED PERSONS "LOOK" DIFFERENT.

THAT ALL PEOPLE IN WHEELCHAIRS ARE ALSO SICK.

THAT ALL DEAF PERSONS CAN'T SPEAK, OR THEY'RE NOT SMART.

THE FACTS ARE:

THAT THE MENTALLY RETARDED DO NOT NECESSARILY LOOK ANY DIFFERENTLY.

THAT PERSONS IN WHEELCHAIRS MAY OTHERWISE BE IN THE BEST OF HEALTH.

THAT MANY DEAF PERSONS CAN LEARN TO SPEAK. ACTUALLY MANY DEAF PERSONS LEARN TWO LANGUAGES...SIGN LANGUAGE AND THEN SPOKEN ENGLISH AS A SECOND LANGUAGE.

THERE ARE OTHER MYTHS ABOUT PEOPLE WHO USE WHEELCHAIRS.

MYTHS THAT THEY CAN'T HOLD A JOB.

IN FACT, PEOPLE FROM MANY DIFFERENT OCCUPATIONS MAY USE WHEELCHAIRS.

ALL WE NEED TO DO IS LOOK BEYOND THE HANDICAP TO THE PERSONS THEMSELVES.

THEN THERE'S THE MYTH THAT WHEELCHAIR USERS CAN'T ENJOY SEX.

THERE'S ALSO THE MYTH THAT THE SIX MILLION RETARDED PERSONS IN THIS COUNTRY ARE OVERSEXED. BOTH MYTHS ARE NOT TRUE!

ANOTHER MYTH ABOUT MENTAL RETARDATION IS THAT THE MENTALLY RETARDED NEVER GROW UP. THEY JUST STAY CHILDREN.

OBVIOUSLY RETARDED CHILDREN DO BECOME RETARDED ADULTS.

FOR A LONG TIME, THESE ADULTS HAVE BEEN TREATED LIKE CHILDREN.

IN FACT, WITH PROPER EDUCATION AND TRAINING, ABOUT 85% OF MENTALLY RETARDED PERSONS CAN BECOME SELF-SUPPORTING.

THEY'RE ABLE TO LIVE AND WORK IN THEIR OWN COMMUNITIES.

THERE'S ALSO BEEN A LOT OF CONFUSION BETWEEN DEVELOPMENTAL DISABILITIES AND MENTAL ILLNESS.

THEY ARE NOT THE SAME, AND THEY DON'T NECESSARILY GO HAND IN HAND.

CHILDREN WITH AUTISM PROBABLY COME UP AGAINST THIS MYTH THE MOST.

HOWEVER, THERE IS NO PROOF THAT ANYTHING IN THE PSYCHOLOGICAL WORLD OF THE CHILD CAN CAUSE AUTISM.

"Spread of Effect"

A VERY COMMON MISCONCEPTION IS USUALLY CALLED THE "SPREAD OF EFFECT".

THIS IS THE BELIEF THAT A HANDICAP IN ONE SENSORY AREA AUTOMATICALLY AFFECTS ALL OTHERS.

SEEING SOMEONE IN A WHEELCHAIR AND ASSUMING THAT THEY ARE ALSO MENTALLY RETARDED IS AN EXAMPLE OF HOW THIS WORKS.

THIS KIND OF ASSUMPTION ISN'T ALWAYS TRUE.

FOR EXAMPLE, SOMEONE WITH CEREBRAL PALSY SO SEVERE THAT THEY CAN'T EVEN SIT UP ON THEIR OWN, MIGHT BE ABLE TO GO TO COLLEGE.

WE OFTEN ASSUME THAT WHEN A PERSON HAS TROUBLE SPEAKING, THEY HAVE NOTHING TO SAY.

ANOTHER EXAMPLE IS CHILDREN WITH LEARNING DISABILITIES AND COMMUNICATION DISORDERS.

THEY NEED SPECIAL EDUCATION, BUT THEY AREN'T MENTALLY RETARDED.

WE CAN'T TALK IN GENERALITIES WHEN WE TALK ABOUT DEVELOPMENTAL DISABILITIES.

DISABILITIES AFFECT PEOPLE IN DIFFERENT WAYS.

WHAT IS TRUE FOR ONE PERSON MAY NOT BE TRUE FOR ANOTHER.

AND OFTEN WHAT MAKES A CONDITION A HANDICAP IS NOT SO MUCH THAT CONDITION ITSELF, BUT OUR REACTION TO IT AND THE REACTION OF OTHERS AROUND US.

WE CANNOT AFFORD TO "HANDICAP" THE HANDICAPPED ANY LONGER.

Section 504

THINGS HAVE BEEN CHANGING.

FOR ONE THING, PUBLIC PLACES ARE EASIER FOR DISABLED PEOPLE TO GET INTO AND USE NOW.

YOU'LL SEE RAMPS LEADING INTO BUILDINGS, WIDER DOORS, BRAILLE FLOOR INDICATORS AND LOWERED WATER FOUNTAINS.

YOU'VE PROBABLY SEEN A BLUE AND WHITE SIGN WITH AN OUTLINE OF A WHEELCHAIR ON IT.

IT'S CALLED THE "SYMBOL OF ACCESSIBILITY".

ALL OF THESE IMPROVEMENTS ARE THE RESULT OF A FEDERAL LAW WHICH PROTECTS HANDICAPPED PEOPLE FROM BEING DISCRIMINATED AGAINST.

IT'S CALLED "SECTION 504"* AND IT APPLIES TO ANY PROGRAM GETTING FEDERAL DOLLARS.

Resources

THERE ARE THREE BASIC RESOURCES YOU SHOULD KNOW ABOUT THAT PROVIDE SERVICES TO THE DISABLED.

PUBLIC LAW 94-142

THE MOST IMPORTANT THING TO REMEMBER IS THAT ALL HANDICAPPED CHILDREN ARE ENTITLED TO AN APPROPRIATE PUBLIC EDUCATION REGARDLESS OF HOW SEVERE THEIR HANDICAP IS.

THAT'S WHAT PUBLIC LAW 94-142 IS ALL ABOUT.

DIVISION OF DEVELOPMENTAL DISABILITIES

EACH STATE HAS AN AGENCY WHICH PROVIDES SPECIALIZED PROGRAMS FOR DEVELOPMENTALLY DISABLED CHILDREN AND THEIR FAMILIES.

SUPPLEMENTAL SECURITY INCOME

THIS IS A FINANCIAL ASSISTANCE PROGRAM FOR DISABLED CHILDREN AND ADULTS.

IT'S SOMETIMES CALLED SSI, AND IT'S MANAGED BY SOCIAL SECURITY.

* of the Vocational Rehabilitation Act of 1973

Summary

WE'VE COVERED QUITE A BIT OF INFORMATION:

WHAT DEVELOPMENTAL DISABILITIES ARE.

MYTHS AND MISCONCEPTIONS.

RESOURCES AND LAWS.

WITH THIS KIND OF INFORMATION WE ARE ALL IN A BETTER POSITION TO:

HELP PEOPLE GET THE SERVICES THEY'RE ENTITLED TO.

KEEP OTHERS INFORMED SO THE MYTHS DON'T CONTINUE.

SUPPORT PROGRAMS FOR DISABLED CITIZENS.

I'D BE HAPPY TO TELL YOU MORE ABOUT MY OWN EXPERIENCES OR ANSWER ANY OF YOUR QUESTIONS.

I'D ALSO LIKE TO KNOW HOW YOU FEEL ABOUT THE THINGS WE'VE TALKED ABOUT.

Be sure to end the question and answer period after 15 minutes.

It's better to end on a high note than to slowly fizzle out.

You could say something like:

I SEE OUR TIME IS UP. I REALLY ENJOYED TALKING WITH YOU. THANK YOU VERY MUCH.

Practice Time

A lot of parents have helped put this talk together. They've been very successful in giving it to many different groups. You can be, too.

It's an easy, straightforward talk to give. It's only about 8 minutes long, but it's packed with information.

Now that you've read the talk, you're ready to start practicing. Here's what to do.

1 STAND UP AND START READING THE TALK.

Reading it silently just won't do.

2 LOOK UP AT LEAST TWO TIMES DURING EACH SENTENCE.

Face to face contact is important.

3 TALK LOUD ENOUGH.

It's frustrating not being able to hear the speaker.

4 USE EXPRESSION IN YOUR VOICE.

Listening to a monotone can be boring.

5 SHOW EXPRESSION IN YOUR FACE.

This helps to get the message across.

Did you give it a try? Don't stop now. It'll get better. Do it again 2 or 3 more times until you start feeling comfortable. 20 to 30 minutes should be enough time for you to complete this exercise.

how's it going?

Ask yourself these questions:

Am I looking up at the "audience" enough or am I staring at my papers?

Am I talking loud enough for the "audience" to hear me or am I mumbling?

Does my voice sound varied, or am I saying every word in the same tone of voice?

Am I showing expression in my face, or am I "deadpan"?

handling nerves

Did you feel nervous?

Well, if you did, it's perfectly natural. All of us get somewhat nervous about public speaking.

The more you practice, the easier it gets to control that nervous feeling. You can even learn to put it to work for you, not against you.

The more familar you are with the talk, the more self-confident you'll feel.

You can do it! Just hang in there and try. The only way to learn how to handle your nerves is to force yourself to get up and give the talk.

How about practicing the talk one more time, just for good measure?

dress rehearsal

Now you're ready for your "dress rehearsal".

Read the talk to someone else - another parent speaker, a family member or a friend.

Ask them to check (✓) you out on the points you've been practicing.

	DOING JUST FINE	NEEDS A LITTLE WORK
Looking up at the audience.	☐	☐
Voice expression.	☐	☐
Facial expression.	☐	☐
Talking loud enough.	☐	☐

10 to 15 minutes should be enough time for you to complete this exercise.

AUDIENCE REACTION

Whole speech was fantastic!

I didn't realize all those things were myths. Thanks for setting me straight.

I got a lot out of your talk... especially the part describing the different disabilities.

Glad to see parents out and getting involved.

Sounds like a great program!

I really feel as though I learned a lot here about disabilities.

I realize now how attitudes handicap the handicapped.

The Fact Sheets

During the question and answer time you may be asked for more information on specific developmental disabilities.

The Fact Sheets will be helpful to you. You will be able to answer specific questions by reading the Fact Sheet information outloud.

You're not expected to be an "expert" or know all of this information by heart.

However, it is important to take some time now to look the Fact Sheets over. Become familiar with what they cover and how to use them.

Parent Speaker Fact Sheets

Developmental Disability : Definition

What is a "developmental disability"?

The term "developmental disability" is defined in PUBLIC LAW 95-602, the "Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978" which was passed on November 6, 1978.

The definition can be found under Title V, Section 503 (Definitions and Special Report) of the Act.

It is very important for all parent speakers to be familiar with this term and to read this definition carefully.

> THE TERM "DEVELOPMENTAL DISABILITY" MEANS A SEVERE, CHRONIC DISABILITY OF A PERSON WHICH---
>
> A) IS ATTRIBUTABLE TO A MENTAL OR PHYSICAL IMPAIRMENT OR COMBINATION OF MENTAL AND PHYSICAL IMPAIRMENTS;
>
> B) IS MANIFESTED BEFORE THE PERSON ATTAINS AGE TWENTY-TWO;
>
> C) IS LIKELY TO CONTINUE INDEFINITELY;
>
> D) RESULTS IN SUBSTANTIAL FUNCTIONAL LIMITATIONS IN THREE OR MORE OF THE FOLLOWING AREAS OF MAJOR LIFE ACTIVITY: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; AND
>
> E) REFLECTS THE PERSON'S NEED FOR A COMBINATION AND SEQUENCE OF SPECIAL, INTERDISCIPLINARY, OR GENERIC CARE, TREATMENT, OR OTHER SERVICES WHICH ARE OF LIFE-LONG OR EXTENDED DURATION AND ARE INDIVIDUALLY PLANNED AND COORDINATED.

Mental Retardation

WHAT IS MENTAL RETARDATION?

Mentally retarded persons mature at a below average rate and experience unusual difficulty in learning, social adjustment, and economic productivity.

The technical definition is:

Significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period.

In terms of IQ scores, mentally retarded persons score below 70.

IQ scores are not sufficient to determine mental retardation. The person must also have difficulty functioning in a way that would be expected for his age and culture.

See Fact Sheet on Defirition of Developmental Disability.

HOW MANY PEOPLE ARE MENTALLY RETARDED?

More than 6 million persons in the U.S.

An estimated 3% of the population.

One in every ten Americans has a mentally retarded person in their family.

More than 100,000 new cases each year.

WHAT CAUSES MENTAL RETARDATION?

Mental retardation can be caused by any condition which impairs development of the brain before, during and/or after birth.

Over 350 causes have been identified. However, in about 3/4 of the cases, the specific cause is unknown.

Some causes are genetic irregularities (either inherited or the result of other factors during pregnancy).

Problems during pregnancy (e.g. german measles, malnutrition, metabolic disorders).

Problems at birth (e.g. Rh factor incompatibility, prolonged labor, reduction in supply of oxygen to the brain).

Problems after birth (e.g. some childhood diseases, glandular imbalance, poisons, malnutrition).

Any person could become functionally retarded due to brain damage resulting from disease or injury.

Mental retardation is not contagious.

WHAT ARE SOME OF THE CHARACTERISTICS?

There are several degrees of retardation.

About 89% of mentally retarded persons are mildly retarded.

6% are moderately retarded.

3.5% are severely retarded.

1.5% are profoundly retarded.

WHAT IS BEING DONE?

Early identification, diagnosis, and intervention programs are important.

Some mental retardation can be prevented through proper medical care and nutrition.

All retarded persons can benefit from education and training.

All retarded children and adults need the same basic services as everyone else-education, health, vocational, recreation, religious and social services, among others.

THIS INFORMATION WAS OBTAINED FROM:

National Association for Retarded Citizens

King County Advocates for Retarded Citizens
Seattle, Washington

FOR MORE INFORMATION

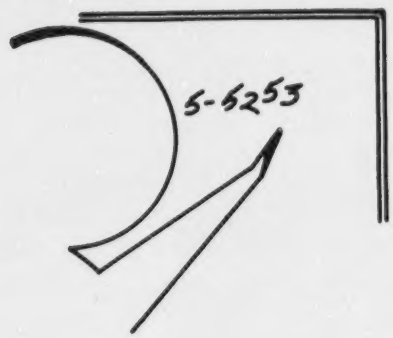
National Association for Retarded Citizens
2501 Avenue J
P.O. Box 6109
Arlington, Texas 76011

American Association on Mental Deficiency
5101 Wisconsin Avenue N.W.
Washington, D.C. 20016

President's Committee on Mental Retardation
Department of Health and Human Services
Office of Human Development Development Services
Washington, D.C. 20201

RESOURCES

(List names, addresses and phone numbers of programs in your community: state, county, local.)



Epilepsy

WHAT IS EPILEPSY?

Epilepsy is a disorder of the central nervous system. Brain cells create abnormal electrical discharges that cause seizures. There are many types of epilepsy and a variety of symptoms: muscle spasms, mental confusion, loss of consciousness.

Epilepsy may be a developmental disability depending on how it affects the individual involved. See Fact Sheet on Definition of Developmental Disability.

HOW MANY PEOPLE HAVE EPILEPSY?

About 2 million in the U.S.

1% of the population.

About 1 in every 100 persons.

WHAT ARE SOME OF THE CHARACTERISTICS?

There are three main types of seizures.

GRAND MAL "Generalized Tonic-Clonic"

May occur at any age.

Symptoms: falling, loss of consciousness, stiffening and shaking of entire body, irregular breathing.

May last one to several minutes.

May occur often (e.g. once a day) or seldom (e.g. once every few years).

First Aid: Stay calm.Don't try to restrain or revive the person.

Remove hazards. Clear the area of any objects which could injure the person.

Don't move the person. Loosen tight clothing, but do not interfere with movements.

Check airways. Make sure breathing is not obstructed. Turn head to side if possible. NEVER TRY TO FORCE MOUTH OPEN.

Allow the seizure to take its course. A doctor's help is needed if the person has one attack after another without regaining consciousness.

When seizure ends, let the person rest.

PETIT MAL "Generalized Non-Convulsive"

Most common in children age 6-14.

Symptoms: blank spells, losing awareness, slight twitching, staring, blinking.

Last only a few seconds.

May occur dozens or even hundreds of times a day.

First Aid: Stay calm. Allow the seizure to take its course.

PSYCHOMOTOR "Partial"

May occur at any age.

Symptoms: period of mental confusion followed by pointless or repetitive movements, pain, dizziness.

Last up to 20 minutes.

First Aid: Stay calm. Do not restrain the person. Be sure they don't hurt themself. Talk to the person calmly. Allow seizure to take its course.

WHAT CAUSES EPILEPSY?

Scientists know how seizures occur, but not why.

Epilepsy can be related to:

- brain injury before, during or after birth,
- head injuries,
- poisons (including lead, alcohol),
- diseases (such as measles, encephalitis),
- disorders of the circulatory system,
- tumors,
- nutritional disorders.

Sometimes the cause cannot be identified.

Epilepsy is not contagious.

Anyone could have an injury or illness that could lead to epilepsy.

But most epilepsy first appears early in life:

30% of all epilepsy shows up before age 5,
34% of cases become evident in the early school years,
13% of cases occur during adolescence, and 23% of epilepsy appears in grown ups.

Males are slightly more likely to have epilepsy.

Heredity usually is not a direct factor in epilepsy. But some kinds of brain wave patterns associated with seizures do tend to run in families.

WHAT CAN BE DONE?

80% of people with epilepsy can be totally or almost totally freed from symptoms through continuing treatment.

Epilepsy can be partly or completely controlled through anticonvulsant drugs. In some cases, special diets or surgery are effective.

Epilepsy need not be a handicap.

But public attitudes and myths about epilepsy often cause more problems for a person with epilepsy than the condition itself.

THIS INFORMATION WAS OBTAINED FROM:

Epilepsy Foundation of America

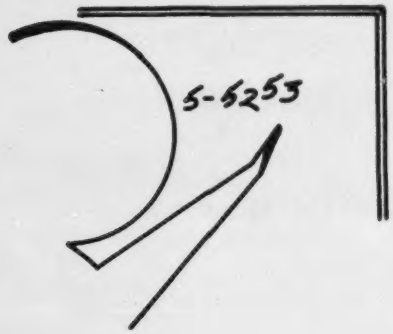
Epilepsy Association of Western Washington
Seattle, Washington

FOR MORE INFORMATION

Epilepsy Foundation Of America
4351 Garden City Drive
Landover, Maryland 20785

RESOURCES

(List names, addresses and phone numbers of programs in your community: state, county, local.)



Autism

WHAT IS AUTISM?

Autism is a neurological condition characterized by severe problems in communication and behavior and an inability to relate to people in a normal manner.

Autism typically appears during the first three years of life although it can be suspected as early as a few weeks or months after birth.

Autism occurs by itself or in association with other disorders which affect brain function.

About 50% of autistic children develop epilepsy.

See Fact Sheet on Definition of Developmental Disability.

HOW MANY PEOPLE HAVE AUTISM?

A general incidence of about 4 in every 10,000 children.

Four times more common in boys than girls.

WHAT CAUSES AUTISM?

Little is known about possible causative factors.

The symptoms indicate a physical dysfunction within the central nervous system -- the exact nature and type of which is unknown.

No known factors in the psychological environment of the child have been proved to cause autism.

It is found in families of all racial, ethnic and social backgrounds.

WHAT ARE SOME OF THE CHARACTERISTICS?

Disturbances in the development of physical, social and language skills.

Abnormal responses to sensations.

Speech and language difficulties.

Abnormal ways of relating to people, objects, and events:
- withdrawn, apathetic, unresponsive
- resistance to change in the environment
- disinterest in people and surroundings
- unusual interest in inanimate objects
- behavioral problems may include self-injurious, repetitive or aggressive behaviors

WHAT IS BEING DONE?

There is a growing body of research in biochemical, sensory stimulation, and behavioral interventions among others. Special education programs using behavioral methods and designed for specific individuals have proven most helpful.

THIS INFORMATION WAS OBTAINED FROM:

National Society for Autistic Children

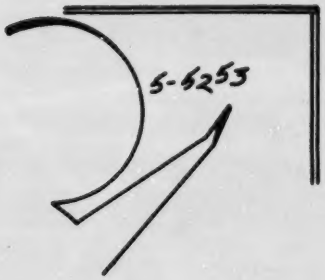
Washington Chapter of National Society for Autistic Children, Seattle, Washington

FOR MORE INFORMATION

National Society for Autistic Children
Suite 1017
1234 Massachusetts Avenue N.W.
Washington, D.C. 20005

RESOURCES

(List names, addressess and phone numbers of programs in your community: state, county, local.)



Cerebral Palsy

WHAT IS CEREBRAL PALSY?

Cerebral palsy refers to a group of neuromotor disorders caused by damage to the brain, usually at the time of birth. Muscles do not function properly. The result may be uncontrollable jerking movements, poor sense of balance, speech and hearing problems, and sometimes retardation.

Cerebral palsy may be a developmental disability depending on how it affects the individual involved. See Fact Sheet on Definition of Developmental Disability.

HOW MANY PEOPLE HAVE CEREBRAL PALSY?

About 750,000 in the U.S.

An estimated 25,000 babies are born each year with cerebral palsy.

In one state survey 6 out of 1,000 babies born had cerebral palsy.

WHAT CAUSES CEREBRAL PALSY?

Sometimes the causes cannot be clearly established.

A number of factors can interfere with development of the brain:

infections during pregnancy,

Rh factor incompatibility,

complications during delivery,

lack of oxygen at birth,

injury or infection.

WHAT ARE SOME OF THE CHARACTERISTICS?

Common types of cerebral palsy include:

SPASTIC	Tense, stiff, contracted muscles.
ATHETOID	Involuntary, uncontrolled motion.
ATATIC	Disturbed sense of balance and depth perception.

Not all people with cerebral palsy are mentally retarded, but physical handicaps can make learning and communication harder.

Speech is difficult for many people with cerebral palsy.

Hearing and vision impairments are also often associated with cerebral palsy.

Seizures (epilepsy) are often present.

WHAT IS BEING DONE?

Some cerebral palsy can be prevented through good medical care and proper nutrition during pregnancy, delivery and infancy.

Early diagnosis is important.

Speech, occupational and physical therapy, among other services, help people with cerebral palsy develop to their full potential.

THIS INFORMATION WAS OBTAINED FROM:

United Cerebral Palsy Association

National Institutes of Health

Easter Seal Society for Crippled Children and Adults of Washington, Seattle, Washington

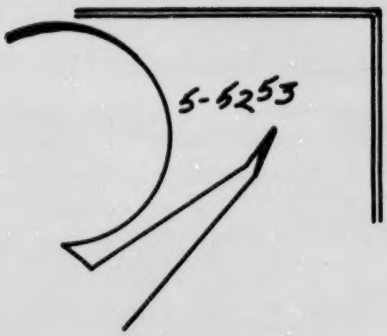
FOR MORE INFORMATION

National Easter Seal Society
2023 W. Ogden Avenue
Chicago, Illinois 60612

United Cerebral Palsy Association
66 East 34th Street
New York, New York 10016

RESOURCES

(List names, addresses and phone numbers of programs in your community: state, county, local.)



Blindness

WHAT IS BLINDNESS?

A person is legally blind if central visual acuity, with corrective lenses, is less than 20/200 or the visual field is less than an angle of 20 degrees.

A legally blind person would not be able to read below the top line of an eye chart.

What a person with normal vision can see at 200 feet, the legally blind person can only see at a distance of 20 feet.

Many persons have severe visual impairments, even though they are not legally blind by definition.

HOW MANY PEOPLE HAVE VISUAL IMPAIRMENTS?

6.4 million people in U.S. with some kind of visual impairment.

About 479,000 are legally blind

About 120,000 are totally blind

60,000 children with severe visual impairment

WHAT CAUSES BLINDNESS?

Persons born blind are said to be congenitally blind. Those who become blind through accident or disease are said to be adventitiously blinded.

Some major causes of blindness:

accidents

diabetic retinopathy (hemorrhages in/on the retina)

cataracts (cloudy/opaque lens)

glaucoma (pressure of fluid in eye is too high)

retinitis pigmentosa (an inherited condition)

In many cases, the exact cause is not known.

WHAT ARE SOME OF THE CHARACTERISTICS?

Most blind persons (over 75%) do have some vision.

Visual impairment can mean overall sight is affected, that only part of visual field is involved, or that only side (peripheral) vision exists.

WHAT IS BEING DONE?

Education and rehabilitation training programs are essential. Rehabilitation includes training in techniques of independent living with little or no vision, followed by specific vocational training (if needed) and placement into a job where full potential can be achieved.

Low vision optical aids enable many partially sighted persons to use their residual sight.

Large print materials, braille books, records and tapes are available.

THIS INFORMATION WAS OBTAINED FROM:

American Foundation for the Blind

National Association for Visually Handicapped

Washington State Commission for the Blind
Seattle, Washington

FOR MORE INFORMATION

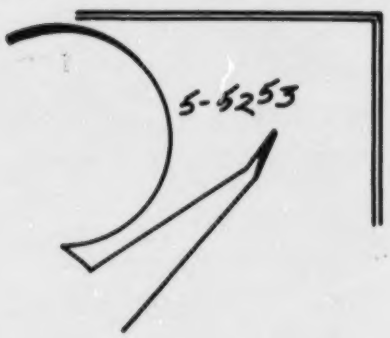
American Foundation for the Blind
15 West 16th Street
New York, New York 10011

National Association for Visually Handicapped
305 East 24th Street
New York, New York 10010

National Association for Parents of the Visually Impaired
2011 Hardy Circle
Austin, Texas 78757

RESOURCES

(List names, addresses and phone numbers of programs in your community: state, county, local.)



Deafness

WHAT IS DEAFNESS?

Deafness involves an inability to hear or interpret sounds.

Most hearing impaired persons hear better in some frequencies than in others.

Only a hearing evaluation can tell how loud sounds must be in order for the hearing impaired person to hear them and at what frequencies (pitches) sounds are heard best.

Deafness may be a developmental disability depending on how it affects the individual involved. See Fact Sheet on Definition of Developmental Disability.

HOW MANY PEOPLE ARE DEAF?

About 1,700,000 deaf people in the U.S.

About 15,000,000 Americans with partial hearing impairments.

WHAT CAUSES DEAFNESS?

There are three main causes of deafness.

CONDUCTIVE LOSS Blocking of the sound traveling to the ear. This can be caused by impacted wax or bone overgrowth.

SENSORINEURAL LOSS Problems with the inner ear or nerves, or auditory centers of the brain. This can be caused by injury, infection, birth defects, loud noises or certain drugs.

CENTRAL DEAFNESS The brain does not interpret sounds properly. This can be caused by tumors or brain damage.

WHAT IS BEING DONE?

The major handicap with deafness is communication.

Deaf people can communicate through spoken words, lipreading, sign language, finger spelling, writing and TTYs (type-writer like instruments that transmit printed words). An audiologist can determine if a person will benefit from a hearing aid. Early diagnosis and special education are important.

THIS INFORMATION WAS OBTAINED FROM:

Seattle Hearing and Speech Center, Inc.
Seattle, Washington

Washington State Department of Social and Health Services

FOR MORE INFORMATION

American Speech and Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852

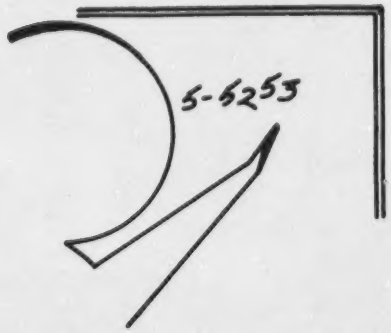
Helen Keller National Center for Deaf-Blind Youth and Adults
111 Middle Neck Road
Sand Point, New York 11050

Gallaudet College for the Deaf
Kendall Green
Washington, D.C. 20002

National Association of the Deaf
814 Thayer Avenue
Silver Spring, Maryland 20910

RESOURCES

(List names, addresses and phone numbers of programs in your community: state, county, local.)



Practice Time

Try your hand at answering these questions outloud.

You will need to turn to different Fact Sheets to do this. Each Fact Sheet is laid out the same way for your easy reference.

This exercise should take about 15-20 minutes to complete. After you've done all 6, turn the page upside down for suggested answers.

1 *What did you mean when you said in your talk "several degrees of mental retardation"?*

2 *I was shopping the other day and saw two people using sign language. Do all deaf people use sign language?*

3 *What is being done for people with cerebral palsy? Will they be like that all their life?*

5 *Our next door neighbor's little boy has epilepsy. What happens when a person has a seizure?*

4 *You mentioned autism in your talk. How can you tell if someone is autistic?*

6 *There are 2 things I'd like to know. Can you tell me when a person is "legally blind" and is a blind person considered "developmentally disabled"?*

(1) Turn to Fact Sheet on Mental Retardation. Look under "Characteristics". (2) Turn to Fact Sheet on Deafness. Look under "What Is Being Done". (3) Turn to Fact Sheet on Cerebral Palsy. Look under "What Is Being Done". (4) Turn to Fact Sheet on Autism. Look under "What Is Autism" and "Characteristics". (5) Turn to Fact Sheet on Epilepsy. Look under "Characteristics". (6) Turn to Fact Sheet on Blindness. Look under "What Is Blindness". Also turn to "Developmental Disability Definition".

important tips

- During the question and answer time, you'll have the opportunity to talk informally with the audience. There's always the remote possibility that someone may not agree with what you say.

  If this comes up, avoid getting into a heated debate or argument. Stay cool. You'll be a winner if you can leave your audience better informed, more aware and glad you came.

- Remember, you will be using the Fact Sheets if someone asks a specific question about a particular disability. If they want more information than you have on hand, give them a resource for further information. Each Fact Sheet has a "For More Information"section.

AUDIENCE REACTION

Good speaker!

I feel I know now what services there are in the community.

I personally am just now widening my viewpoints regarding the handicapped .... the realization that they too have a potential and a place in society.

I didn't know how many types of handicaps there are.

I didn't realize so many retarded people can hold a job.

I didn't realize how many handicapped children there are in the U.S.

The Resource Sheets

It is not unusual for people in the audience to ask for information about community resources.

The Resource Sheets list names, addresses and phone numbers of some key agencies which help people get in touch with the information or services they need. They also contain a listing of parent and professional organizations which can be particularly helpful to parents of developmentally disabled children.

Please take some time now to become familiar with this information.

You may want to update these resource sheets periodically because addresses and phone numbers change from time to time.

Parent Speaker Resource Sheets

Information & Referral

Information & Referral programs help people identify and locate needed services and information. They may also advocate on behalf of the person to make sure that services are provided. List information and referral agencies for your community.

Written Material

CLOSER LOOK

BOX 1492

WASHINGTON, D.C. 20013

Closer Look is a national information center for parents of children with handicaps. They provide information on parent organizations, right to education laws, how to work with schools, books and pamphlets about disabilities, what you need to know about testing and evaluations plus other practical information covering childhood to adulthood.

Parent & Professional Organizations

Autism

National Society for Autistic Children
Suite 1017
1234 Massachusetts Ave. NW
Washington, D.C. 20005

Blind

American Council of the Blind
1211 Connecticut Ave. NW
Suite 506
Washington, D.C. 20036

American Foundation for the Blind
15 West 16th St
New York, New York 10011

National Association for the Visually Handicapped
305 East 24th St
New York, New York 10010

National Federation for the Blind
1800 Johnson St
Baltimore, Maryland 21230

National Association for Parents of the Visually Impaired
2011 Hardy Circle
Austin, Texas 78757

Association for the Education of the Visually Handicapped
919 Walnut St
Philadelphia, Pennsylvania 19107

Cerebral Palsy

United Cerebral Palsy Association
66 East 34th St
New Tork, New York 10016

Deaf

Alexander Graham Bell Association for the Deaf
3417 Volta Place NW
Washington, D.C. 20007

National Association of the Deaf
814 Thayer Ave
Silver Spring, Maryland 20910

International Association of Parents of the Deaf
814 Thayer Ave
Silver Spring, Maryland 20910

International Parents' Organization
Alexander Graham Bell Association for the Deaf
3417 Volta Place NW
Washington D.C. 20017

Deaf-Blind

Helen Keller National Center for Deaf Blind Youth and Adults
111 Middle Neck Road
Sand Point, New York 11050

American Association of the Deaf-Blind
1220 East-West Highway Suite 711
Silver Spring, Maryland 20910

Mental Health

Mental Health Association, National Headquarters
1800 North Kent St
Arlington, Virginia 22209

American Academy of Child Psychiatry
1424 16th St NW Suite 201A
Washington, D.C. 20036

American Association of Psychiatric Services for Children
1725 K St NW
Washington, D.C. 20016

American Psychological Association
Division of Child & Youth Services
1200 17th St NW
Washington, D.C. 20036

Epilepsy

Epilepsy Foundation of America
4351 Garden City Drive
Landover, Maryland 20785

Health Impairments

American Cancer Society
777 Third Ave
New York, New York 10017

American Heart Association
7320 Greenville Ave
Dallas, Texas 75231

Cystic Fibrosis Foundation
6000 Executive Building
Suite 309
Rockville, Maryland 20852

Juvenile Diabetes Foundation, Intl
23 East 26th St
New York, New York 10010

National Hemophilia Foundation
19 West 34th St Room 1204
New York, New York 10001

American Kidney Foundation
7315 Wisconsin Ave
Bethesda, Maryland 20814

National Tay-Sachs & Allied
Diseases Association
92 Washington Ave
Cedarhurst, New York 11516

Learning Disabilities

Association for Children with
Learning Disabilities
4156 Library Road
Pittsburg, Pennslyvania 15234

Orton Society
8415 Bellona Lane
Towson, Maryland 21204

Mental Retardation

National Association for Retarded
Citizens
PO Box 6109
Arlington, Texas 76011

American Association on Mental
Deficiency
5101 Wisconsin Ave NW
Washington, D.C. 20016

President's Committee on Mental Retardation
US Dept. Health & Human Services
Office of Human Development
Washington, D.C. 20201

Down's Syndrome

Down Syndrome Congress
PO Box Drawer 1527
Brownwood, Texas 76801

Sharing Our Caring
PO Box 400
Milton, Washington 98354

Speech Impairments

American Speech & Hearing Association
10801 Rockville Pike
Rockville, Maryland 20852

National Association for Hearing and
Speech Action
10801 Rockville Pike
Rockville, Maryland 20852

Physically Handicapped

Muscular Dystrophy Association
810 Seventh Ave
New York, New York 10019

Arthritis Foundation
1314 Spring St NW
Atlanta, Georgia 30309

National Multiple Sclerosis Society
205 E 42nd St
New York, New York 10017

National Spinal Cord Injury
Foundation
369 Elliott St
Newton Upper Falls, MA 02164

Spina Bifida Association of
America
343 South Dearborn St Room 319
Chicago, Illinois 60604

All Disabilities

National Easter Seal Society for
Crippled Children & Adults
2023 W Ogden Ave
Chicago, Illinois 60612

March of Dimes Birth Defects
Foundation
1275 Mamaroneck Ave
White Plains, New York 10605

The Association for the Severely
Handicapped
7010 Roosevelt Way NE
Seattle, Washington 98115

Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091

American Coalition of Citizens
with Disabilities
1200 15th St NW
Washington, D.C. 20005

National Center for Law and the
Handicapped, Inc.
1235 North Eddy St
South Bend, Indiana 46617

Practice Time

This time practice answering these questions outloud using the Resource Sheets for reference. This should only take a few minutes. Again, after you're done, turn the page upside down for suggested answers.

1 *I know someone with a 30 year old disabled daughter who just sits at home all day. Is there any help for her?*

2 *I'd like to know more about all of this. Could you recommend a book or something like that?*

3 *Where can I get in touch with other parents? We don't know many other people with a hearing impaired child.*

4 *My sister is moving here and her child has cerebral palsy. She's going to need a school program, a doctor, and all sorts of things. Do you have any suggestions?*

(1) Give several of the Information & Referral numbers. (2) Give address for Closer Look. If person is interested in a specific disability, give names of parent/professional organizations. (3) Give names of parent/professional organizations. Also, refer to resources on Fact Sheet on Deafness. (4) Give several Information & Referral phone numbers. Can also give resources listed on Fact Sheet on Cerebral Palsy.

important tips

- When someone tells you about a problem you may be tempted to offer a solution right then and there. This is not a good idea.

  As you're probably aware, problems are often more complicated than they seem on the surface. The way to be most helpful is to make a referral to people who specialize in getting services for developmentally disabled people. Use your Resource Sheets when this type of question comes up.

- You're not expected to be an "expert". If you're asked a question that you don't have the answer to, just say, "I don't know, BUT I can give you the number of a place where you can find out." Refer to the Resource Sheets or the "For More Information" section in each Fact Sheet.

- Remember, you'll be using the Resource Sheets when people ask for help for a developmentally disabled person (services such as evaluations, schools, medical, etc.)

AUDIENCE REACTION

Your speech was very interesting!

I felt the most important point you made in the talk was the part about not thinking of all handicapped people as being the same.

I work with a girl with cerebral palsy, and the first thing a friend asked me was "does she look retarded?" That's just the kind of thing you mentioned.

Really good job.

Now I can see how important it is to get information right away when something is wrong with your child.

Reaching Out

Congratulations!

Congratulations! You've completed the Handbook. Now you're ready to reach out to your community.

The first thing you'll need to do is schedule some talks. You'd be surprised how many groups in your community would be interested in having a parent speaker like you. Here's a simple way of getting started.

- Think about groups you may already belong to.
- Think about people you know who belong to other groups.
- Parent speakers have given talks to:

  BUSINESS, CIVIC & FRATERNAL ORGANIZATIONS

  PROFESSIONAL GROUPS

  HIGH SCHOOL & COLLEGE CLASSES

  CHURCH GROUPS

  PARENT GROUPS

  SENIOR CITIZEN GROUPS

  SOCIAL CLUBS

- There's no limit to the number and types of groups you can talk to.

- Let people know you're out there. Contact groups and tell them about the parent speaker talk.

- Stick with it. Sometimes you have to make several contacts before you line something up.

DON'T BACK OUT NOW!

You've never done anything like this before? None of the other parent speakers had either.

Go ahead! You really can do it. Schedule and give some talks. This is your opportunity to make a real impact on your community.

As a parent speaker, you need to reach out to other parents too.

Tell parents what you're doing and how they can get involved. The more parents get involved, the greater the impact on the community. Some parent groups might even want to take this on as a project.

Here are some ideas for training other parents:

- Parents should have their own copy of Reaching Out.
- Ask them to read their copy through and complete the exercises. (A week is plenty of time.)
- Set a time & place to meet. Use this time to give the talk to them. Since you've already given the talk "for real" you can be sort of a model for them. Then have them give the talk to you. Offer suggestions and provide encouragement.
- Help them "brainstorm" all the different groups in the community where they could give the talk.
- If possible, go with them to their first talk to help them feel at ease.
- When they start giving more talks and training other parents, continue to do whatever you can to be helpful.

We believe that the combined efforts of parent speakers will ultimately promote better community understanding and awareness. We hope that you, like other parent speakers, will find the challenge of *reaching out* to your community a rewarding and satisfying experience.

A Word of Thanks

This handbook could not have been completed without the help, support and advice of a dedicated group of parents. The following parents provided us with feedback at each step in the development of this program, helped us prepare the parent speakers talk, and tested out materials in this handbook. We thank them for their willingness to share of themselves and their committment to this program.

Sandy Center

Val Eyer

Sharon Long

The following community groups also helped in the development of this handbook by providing us with specialized information about developmental disabilities and critiquing the information contained in each of the Fact Sheets. Their suggestions and advice have been extremely valuable.

Epilepsy Association of Western Washington

King County Advocates for Retarded Citizens

Seattle Hearing & Speech Center, Inc.

United Cerebral Palsy Association of King-Snohomish Counties

Washington Chapter of the National Society for Autistic Children

Washington State Commission for the Blind

We also wish to thank the staff of the *Experimental Education Unit, Child Development and Mental Retardation Center, University of Washington, Seattle, Washington* for their assistance and encouragment and the *King County Board for Developmental Disabilities* for their support of the Parent Speakers Program.

PROGRAM GUIDE

Changing Community Attitudes

Your community, like most others, may be faced with critical issues affecting the lives of disabled citizens.

Communities are being asked to make decisions about mainstreaming, deinstitutionalization, legislation and expanded community services. An informed and knowledgeable community, aware of the needs and rights of disabled citizens, can make a difference in the way these issues are handled.

A Parent Speakers Program is a direct "person to person" way to inform and educate the community.

HOW A PARENT SPEAKERS PROGRAM HELPS

In this program, parents of developmentally disabled children volunteer to be community speakers. Through presentations to groups, organizations and agencies in the community, parent speakers provide factual information on disabilities, on myths and misconceptions about handicaps, and on helping agencies and advocacy groups. Following the presentation, a discussion time and question/answer period is set aside in order to share personal experiences. After listening to the first hand accounts of parent speakers, participants can identify with and become more sensitive to the needs of disabled citizens. In addition, participants become more aware of available resources and better able to find needed services.

PARENT POWER

Parent speakers are taking positive steps to improve services for their own children and to create a more accepting community atmosphere for all disabled persons.

Parents are particularly credible and persuasive in impacting community attitudes. First hand information and experience make them successful advocates in eliciting community support and awareness.

Perhaps your parent group has been searching for a new focus of activity, a way to get involved, or a way to make their childrens' needs better understood by the community. Your group will find a Parent Speakers Program a challenging and worthwhile project to undertake.

IT DOES MAKE A DIFFERENCE

A Parent Speakers Program directly impacts the community that it reaches, the sponsoring parent group or agency, individual parent speakers, and disabled citizens. It does make a difference.

Increases public awareness

Changes public attitudes

Creates a more accepting community atmosphere.

Focuses attention on a segment of the population historically discriminated against.

Improves relations between the community and agencies providing services to the disabled.

Enables parents to get involved and take constructive action.

Helps improve services for disabled citizens.

HOW TO USE THIS GUIDE

Since the initial development of the Parent Speakers Program, we have assisted a number of parent groups in starting up their own speakers programs. Many groups suggested that it would be helpful to have a written set of guidelines.

This Program Guide contains information and materials needed to implement a Parent Speakers Program, and is meant to supplement the basic material presented in main text of Reaching Out. References to Reaching Out are made throughout the Guide.

We hope this Program Guide will be helpful to you in the development of your program.

Orientation

Parent speakers can be any parent, mother or father, of a developmentally disabled child, regardless of the child's age or disability. The program appeals to parents from many different backgrounds. No previous experience in public speaking is necessary or required. The only requirements are a:

Committment to the goals of the program.

Willingness to give at least two talks.

Attendance at a 1½ hour training session.

Willingness to get involved and give it a try.

Desire to help others.

PURPOSES

The purposes of orientation are to give parents an understanding of the overall workings of the program and to provide enough information so that parents can reach a decision about their participation.

PROCEDURES

The following procedures are recommended to orient parent speakers to the program.

1. Contact parent and describe the program. Include in your description:

Benefits of participation.

Importance of parent involvement.

Impact that speakers make on community attitudes.

Assurances that no previous experience in public speaking is necessary.

1½ hour training session is all that is needed.

Time committment is flexible.

Parents are particularly credible speakers.

It's an enjoyable, rewarding activity.

Review pages 2-3 in Reaching Out for additional ideas.

2. Point out specific sections in each parent's book.

page 4.....description of book

page 5.....the Talk

page 17.....Fact Sheets

pages 38-42....Resource Sheets

pages 14-16, 36-37...Practice Exercises

Tell parent speakers to:

Familiarize themselves with the book but not memorize material

Complete the practice exercises prior to the training session.

3. Schedule a 1½ hour training session for each speaker and describe the training activity. Tell the parent that they will have an opportunity to:

Ask questions about material in the book

Listen to you give the talk

Watch how you handle "questions" from the "audience"

Practice handling "questions"

TRAINING SESSION AGENDA

ACTIVITY	AMOUNT OF TIME	REACHING OUT (page numbers)
Answer questions	10 minutes	
Demonstrate talk	15 minutes	6 - 13
Demonstrate questions & answers	10 minutes	36, 43
Discussion	10 minutes	14 - 16
Practice talk	15 minutes	6 - 13
Practice questions & answers	10 minutes	36, 43
Discussion	10 minutes	37, 44
Summary	10 minutes	
TOTAL TRAINING TIME: 1½ HOURS		

Training Tips

DEMONSTRATE THE TALK (approximate time: 15 minutes)

Give the parent speaker talk. This demonstration will serve as a model for the new parent speaker.

Before you demonstrate the talk, explain the five practice tips described on page 14 of Reaching Out. This will help the parent speaker cue into basic public speaking skills.

When you give the talk, try to give it as realistically as possible. Pretend there is an audience. Stand up, speak loudly and use gestures.

This is the time for "best foot forward", so that the new parent speaker gets a chance to see public speaking skills in action. If you do make a mistake or slip, mention it afterwards. Chances are it will have gone unnoticed. The new parent speaker will be reassured to know that slips do happen, and will learn from your example how to handle them calmly.

Following the talk, demonstrate responses to audience questions. Complete these two activities before proceeding to the discussion time.

DEMONSTRATE RESPONSES TO QUESTIONS (approximate time: 10 minutes)

The training session will be more realistic if, in addition to demonstrating the talk, you demonstrate responding to audience questions as well.

After you give the talk, have the new parent speaker ask you three or four questions. Refer to pages 36 and 43 in Reaching Out for sample questions.

This is an opportunity to demonstrate the use of the Fact Sheets and the Resource Information.

DISCUSSION (approximate time: 10 minutes)

During this time, answer any questions the parent speaker may have. Some additional points to make are:

How to use basic public speaking skills: eye contact with audience, voice expression, facial expression, voice volume

How to control that "nervous" feeling

How to use the Fact Sheets to back up answers to questions

How to use the Resource Information to provide appropriate referrals

PRACTICE THE TALK (approximate time: 15 minutes)

The parent speaker now has an opportunity to practice giving the talk. You become the "audience".

Instruct the parent speaker to give the complete talk as though it were an actual presentation. Some parents may feel embarrassed or silly about practicing the talk in front of you. You can reassure them that's to be expected; it's one of the reasons for having the training session.

But after they complete the training session and the at-home dress rehearsal, they will be accomplished parent speakers.

PRACTICE RESPONSES TO QUESTIONS (approximate time: 10 minutes)

Refer to pages 36 and 43 in Reaching Out for sample questions to ask the parent speaker.

DISCUSSION (approximate time 10 minutes)

Give lots of support and encouragement.

Point out what was done well before bringing up areas for further practice.

Answer any questions that come up about the talk.

HOME PRACTICE

Encourage parent speakers to:

- Practice the talk at home out loud, preferably in front of another person
- Try to look up one or two times each sentence
- Vary voice volume and inflection
- Use facial expressions and gestures appropriately
- Review the Fact Sheets until they can find and use them easily
- Become familar with the Resource Information, particularly referral information

Refer to pages 37 and 44 in Reaching Out for suggestions to give parent speakers on:

- Handling "hostile" questions
- Responding to personal problems
- Answering difficult questions
- When to say "I don't know"

Organization

The Parent Speaker Program can be organized and administered without a lot of time and paperwork. The major organizational steps are 1) contacting community groups 2) arranging talks 3) assigning speakers 4) re-confirming the talk and 4) post-talk discussion with speakers.

CONTACTING COMMUNITY GROUPS

The Parent Speakers talk is suitable for many different types of groups. No doubt there are lots of groups and organizations right in your own community that will be interested in this information.

Some possibilities are:

Community Clubs
Fraternal Organizations
Civic Organizations
Business Organizations
Professional Groups
University Classes
Community College Classes
High School Classes
Church Groups
Parent Groups
Social Service Agencies
Hospitals and Clinics
Social Clubs
PTSAs

Can you think of others?

Use the MASTER LIST OF COMMUNITY ORGANIZATIONS included in this Program Guide to keep track of the groups in your area.

There are a number of ways to inform the community about your Speakers Program.

Phone Calls

Letters

Personal Visits

Flyers/Brochures/Posters

Announcements in Newsletters/Bulletins

Public Service Announcements: Radio/TV

Newspaper Features and Articles

In talking to groups about your Speakers Program, be sure to include the following information:

Your name and organization

How long your Parent Speakers Program has been operating

Purposes of your program

Types of information included in the talk

Length of talk

Value of a parent's perspective

Significance of this information to that particular group

Point out the uniqueness of this type of presentation.

Factual information on disabilities

PLUS

Direct personal experiences of a parent and child

ARRANGING TALKS

It works out best if the Parent Speakers Talk is scheduled as part of a regularly scheduled meeting of a group.

There are several things you will want to find out beforehand in order to prepare the speaker for the talk: when, where, who, why. Guidelines for getting this information are provided on the next page.

The TALK SCHEDULING FORM included in this Program Guide can be used to record information about the talk.

WHEN	Time of talk (beginning and ending)
	Time of group meeting
	Date, day
WHERE	Complete address
	Ask for directions and/or map, if needed
	Ask about parking
WHO	Is the group composed of professionals, parents, or general public?
	Has the group ever heard other talks about disabilities from other speakers?
	Does the group generally ask a lot of questions?
WHY	What generally goes on at this group's meetings?
	Where does the talk fit in?
	Should the speaker stay for the entire meeting?
	Are there any areas they are particularly interested in?

ADAPTING THE TALK

Most public speakers adapt their speeches to fit the type of audience they will be talking to.

Not all audiences are the same, and different groups respond better to different approaches. Here are some ways you can help parent speakers adapt the talk for a variety of groups.

For General Audiences

Suggest that speakers share personal experiences at appropriate points in the talk. For example:

A myth or misconception about handicaps that has affected the parent speaker personally.

What it was like for the speaker's child before P.L. 94-142 was passed and how it's different now.

Programs and services that have been particularly important to the speaker's family and experiences getting and using those services.

For High School Groups

Shorten the talk and describe the child's condition in down to earth terms.

Parent speakers can take their children with them, if appropriate, so the group can interact with a disabled person. Parents who have done this have had warm, enthusiastic receptions.

Speakers can share how their family interacts with their child to help the group learn that a disabled child is not so very different from other children.

For Professional Groups

Suggest that speakers omit any information that the group may already know. Avoid putting the profession "down".

Speakers can talk about their own experiences using professional services so that the group can understand the "other side of the coin".

Show how the information relates to professional work. For example:

As doctors, you can dispell these myths.

As teachers, you can help parents locate services they need.

For Parent Groups

Suggest that speakers give some background information on the Parent Speakers Program. Some parents in the group may be interested in becoming parent speakers.

Speakers can pay special attention to the Resource Information and the listing of Parent and Professional Organizations. This information is usually of great interest to parents.

ASSIGNING SPEAKERS

Because all parent speakers give the same talk, assigning parent speakers is relatively easy.

Some parent speakers may have a preference as to the type of group or age range they would like to address. In fact, some speakers may wish to "specialize" in speaking to just one type of group (for example, high schools or church groups).

Transportation needs and time schedules may also be factors in assigning speakers.

Sometimes a community group will express an interest in hearing from a parent whose child has a specific disability (such as Down Syndrome or deafness.

You can use the PARENT SPEAKER REGISTRATION FORM included in this Program Guide to help in assigning speakers.

RE-CONFIRMING THE TALK

A phone call a day or two ahead is usually all that is necessary to re-confirm the scheduled talk. It's a good policy to do this just in case there are some last minute changes.

POST-TALK DISCUSSION WITH SPEAKERS

You and the parent speakers will want to talk over their experiences giving talks. The speakers will want to share with you what took place. It's the perfect time for you to compliment them on a job well done.

It's helpful to use the FEEDBACK FORM included in this Program Guide to focus discussion on the audience's reaction to the talk.

The FEEDBACK FORM enables the parent speaker to see the impact made on the group's knowledge and awareness.

The FEEDBACK FORM is also beneficial to the audience. Completing the form enables the audience to summarize and remember the most important points. It gives them an opportunity to express their thoughts and evaluate their attitudes. It demonstrates their increased awareness and knowledge.

PARENT SPEAKERS PROGRAM

REGISTRATION FORM

NAME:_____PHONE NUMBER:_____

ADDRESS:_____

CHILD'S AGE:_____CHILD'S SCHOOL:_____

Please check times most convenient for you:

____ MORNINGS ____ AFTERNOONS ____ EVENINGS

Please check days of week most convenient for you:

___MONDAY ___TUESDAY ___WEDNESDAY ___THURSDAY ___FRIDAY

Please check transportation needs:

____ Can provide own transportation

____ Will need transportation

____ Must be near bus route or my home

Do you belong to any organizations which you think might be interested in a Parent Speaker Talk? If so, please list:

Do you have any contacts (friends, relatives, neighbors) who belong to organizations which might be interested in a Parent Speakers Talk? If so, please list:

Do you know of any other groups which might be good places for a talk? If so, please list:

I UNDERSTAND MY RESPONSIBILITIES AS A PARENT SPEAKER AND WISH TO PARTICIPATE IN THIS PROGRAM.

_____
Signature

PARENT SPEAKER TALK

SCHEDULING FORM

DATE:_____TIME OF TALK:_____

NAME OF GROUP:_____

ADDRESS: _____

DIRECTIONS: _____

_____PARKING:_____

CONTACT PERSON:_____PHONE NUMBER:_____

What type of group is this?

Why did they request a talk?

Are there any special instructions for the speaker?

ASSIGNED SPEAKER:_____PHONE:_____

PARENT SPEAKER ROSTER

NAME	ADDRESS	PHONE NUMBER

MASTER LIST OF COMMUNITY ORGANIZATIONS

NAME	CONTACT PERSON & PHONE	CONTACTS	DATE CONFIRMED

PARENT SPEAKERS PROGRAM

FEEDBACK FORM

I enjoyed the opportunity to speak to this group and would appreciate feedback from each of you about the information presented.

Would you please take a few minutes to complete this form?

Please list the points made in the talk that you felt were most important.

1.

2.

3.

4.

5.

Please list the information that was most helpful to you personally.

1.

2.

3.

4.

5.

Any other comments?

THANK YOU

Additional Resources

ABOUT PUBLIC SPEAKING

Carnegie, Dale. How to develop self-confidence and influence people by public speaking. New York: Pocket Books, 1971.

Oliver, Dr. Robert T. Communication and leadership program. Santa Ana, California: Toastmasters International, 1969.

Sarnoff, Dorothy. Speech can change your life. New York: Dell Publishing Company, Inc., 1972.

Stone, Janet, & Bachner, Jane. Speaking up: A book for every woman who wants to speak effectively. New York: McGraw Hill Book Company, 1977.

ABOUT PUBLIC EDUCATION AND AWARENESS

When you meet a handicapped person...Fifteen hints for rewarding relationships.

National Easter Seal Society
2023 W. Ogden Avenue
Chicago, Illinois 60612

Producing a public relations program for disabled adults.

President's Committee on Employment of the Handicapped
Washington, D.C. 20210

The invisible battle - Attitudes toward disability

Beyond the sound barrier.

Free wheeling.

Counterpoint.

Dignity.

Series on attitudinal barriers facing disabled citizens.

Regional Rehabilitation Research Institute on Attitudinal, Legal and Leisure Barriers
1828 L Street, N.W.
Suite 704
Washington, D.C. 20036

How to make friends and influence the media.

Institute for Information Studies
400 North Washington Street
Suite 202
Falls Church, Washington 22046

Attitudes of the general public toward handicapped individuals.

White House Conference on Handicapped Individuals
Volume One: Awareness Papers
Clearinghouse on the Handicapped
Washington, D.C. 20201

NEWSLETTERS AND BULLETINS

Common Sense from Closer Look
Parents' Campaign for Handicapped Children and Youth
Box 1492
Washington, D.C. 20213

Disabled USA
President's Committee on Employment of the Handicapped
Washington, D.C. 20210

Handicapped Americans Reports
2626 Pennsylvania Avenue N.W.
Washington, D.C. 20037

Amicus
National Center for Law and the Handicapped, Inc.
1235 North Eddy
South Bend, Indiana 46617

In addition to the newsletters listed above, many of the parent and professional organizations listed on pages 40-42 in Reaching Out also publish newsletters and bulletins.